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ABSTRACT

Based on the experiences of a child advocacy project in Tennessee entitled County Agents for Children, the booklet presents a guide to help identify the needs of specific children, and to assist child advocate volunteers and other community personnel in meeting these needs. The focus is on children whose learning speed or physical development is slowed or delayed. Aspects covered include the developmentally delayed child, individualized instruction, legislation for education of the handicapped, toilet training, parental denial of a problem, places to look for needy children, parents' rights, troubled teenagers, the juvenile offender, communication problems, listening, sexual development, mental retardation and prejudice, adult activity centers, deviancy, normalization, state agencies, and crisis management. (DLS)

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FINAL REPORT

PART II

Project Number 223553
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COUNTY AGENTS FOR CHILDREN

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PREFACE

HELPING CHILDREN EFFECTIVELY, A Guide to Volunteers, is the first of two booklets prepared for those who want to help children in their communities. This material is the result of a project called County Agents for Children based at the George Peabody College for Teachers, Nashville, Tennessee, and jointly funded by the Bureau of Education for the Handicapped, the National Institute of Mental Health, and the Rehabilitation Services Administration.

The material includes many approaches to looking at the needs of children and matching community resources to meet those needs. The book is a compilation of ideas and experiences drawn from the work of County Agents based in four separate counties in Tennessee. It reflects helpful ways that they found to identify needs and to assist volunteers and other community resources to meet the needs of a specific child.

The other booklet discusses helping communities help children and meet needs through community awareness. These two booklets -- a part of the final report of County Agents for Children -- provide basic resources for helping individuals and groups utilize their resources better to meet the needs of particular children in their communities.

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HELPING CHILDREN EFFECTIVELY

CHILD NEEDS AND CHILD HELPERS

Every child has some needs, but a few children have such great needs that parents must have outside help early. County Agents for Children have seen dozens of people from every walk of life discover both the rewards of working for children in their community and a surprising amount of skill in problem solving.

Working with these volunteers we have watched and listened and learned from them. Now we can pass on to you ideas and methods to assure that you will be able to see that your young friend's need is met well. The needs of children in the critical stages of their life are defined, and resources are given for you to use to meet those needs. Your involvement is necessary to help the child, our greatest natural resource, develop his maximum potential.

HANDICAPPED CHILD'S NEEDS EASIER TO DEFINE

Every child has developmental tasks that require some assistance from "big people." Every child needs love, protection, and guidance; however, a handicapped child's needs stand out bigger and clearer than the needs of other children. We will focus particularly on those children whose learning speed or physical development is slowed or delayed. When you learn to identify the needs of a specific child, you will be able to meet the needs of many others more effectively.

YOU AS A HELPER

Do you qualify to help children? Are you alive and willing? Then you qualify. Most of the child helpers the County Agents worked with had no special preparation. Often they said, "I wouldn't mind helping, but I would not know what to do, how to go about it, how to get it together in efficient order." They discovered that with the kind of resources given in the following pages, they were able to become an important resource for some child.

ANTICIPATION Some children will need much more help than others. A parent is often stunned by the birth of a child with a handicap. Parents anticipate a baby having certain needs, but a crippled child or a mentally retarded child usually catches them totally unprepared. This booklet will help parents and helpers know some things to do when they are faced with special problems of a child.

THE DEVELOPMENTALLY DELAYED CHILD The child whose learning speed or physical development is slowed or delayed requires special attention from helpers in the community. Looking at the needs and problems of these delayed children is a lot like watching a large-screen slow-motion replay. The important steps are easier to pick out and analyze. The needs of delayed children and their families are much like those of normal children all the way from birth to adulthood. When you learn the ABC's of helping handicapped or delayed children, you will feel more comfortable with other child-helping tasks.

CRITICAL LIFE STAGES Parents enter a critical stage when they first discover that their child has some developmental delay because of cerebral palsy, an accidental injury, mental retardation, or some learning disability. The second critical stage comes during the toddler period when the effect of the disability is seen on the rate at which the child moves, talks, and learns. The third critical stage comes when the child reaches school age. The fourth critical period comes when the child reaches puberty or adolescence. The fifth critical stage comes when the child finishes the "school age period" and enters into some area of adulthood. Each of these stages require the assistance of helpers. What can you do? If you care enough to ask this question, then read on.

COUNTY AGENT'S STRATEGY In Tennessee, County Agents for Children worked in three different counties identifying ways to assess the needs of children and to utilize

community people to meet those needs. We looked for unmet instrumental and unmet expressive needs. Instrumental needs required someone to act as an instrument to provide a specific service such as transportation, food, or medical care. Expressive needs required someone to care for them as a person, spend time with them, and express a personal interest. Often individuals volunteered to give services to help a specific child. On other occasions, an organization or agency met the needs. Frankly, some needs have not been met by any available resource that was discovered or developed. Many counties still need someone like a County Agent for Children who can locate and assist volunteers like you to help recognize and meet the needs of a child.

FRUSTRATIONS FACED

Being a helper sometimes has its difficulties. It is difficult for some people to admit they need help. It is also difficult for schools and other institutions to adjust their programs at times to meet special needs. The frustrations are numerous, but volunteers can do much to meet the unanticipated needs of children.

THE CHALLENGING WORLD OF MENTAL RETARDATION

The mentally retarded (developmentally delayed) child learns more slowly than other children. Some delayed children have obvious physical differences such as the Down's syndrome child, with slightly different eyes and hands and the ability to bend his body further than normal, but many delayed children differ very little from normal and are not recognized until they reach school age.

RICHER TEACHING FOR POOR LEARNERS

A child with an I.Q. of 75 is only mildly delayed, but a child with an I.Q. of 100 can learn about 33% faster. A child with only a 50 I.Q. has to work much harder to learn. Though most parents are

not trained teachers and just "do what comes naturally," they find their child learns rapidly during the first four years. He achieves as much as 50% of his intellectual growth during this period almost automatically. This is less true with a delayed child or a child that doesn't have a healthy, natural home life. These delayed children need enriched teaching during this period. If a child gets additional early stimulation, he can be ready to compete more adequately when he reaches kindergarten or school age. So early recognition, attention, and extra training is essential.

RECOGNITION

Moderate and profoundly injured or delayed children are often recognized at birth because of physical signs. With others, the signs may escape notice or not show up until later. More than 3 our of every 100 children in your community has some retardation or problems that delay development, but parents do not expect their child to be retarded. Some crises are expected.

CRISES:
NOVELTY
RELIGIOUS
REALITY

Parents often need help in facing the crises which follow recognition that their child is retarded, injured, or delayed in learning ability. One of these crises may be called the novelty crisis. Parents are likely to be overwhelmed by having a child that does not fit "the pattern." Every child is different, so the real cause of this crisis is the mystery associated with words like "retarded," "palsied," "learning disabled," and the like. These words bombard the mind with vague images, questions, and fear of the unknown. Some parents also face a religious crisis at this time in which they blame themselves for their child's condition. At about the same time, the reality crisis is thrust upon the parent. He accepts the child as his own but will still have additional tasks, expenses, maybe drudgery, and other real problems. "How do I provide for the child? How much will it cost me? Where can I get help? What will my friends think?" The day-by-day care and expense of caring for a delayed child ofttimes may take more energy and resources than the parents can provide. This

is especially true if the novelty and religious crises are allowed to continue sapping their energy.

NOVELTY CRISIS

The novelty crisis may be compared to a person walking into a World's Fair for the first time. He is overwhelmed by newness and potential cost. He wants a map that describes what is there, how to get through it, and what it costs. This crisis begins immediately and continues with an increasing number of questions and needs. Fortunately, there are answers; and helping people like you can assist parents to get the answers.

WHAT CAN WE DO FOR A CHILD

When a parent is given specific information on what his child needs and what he can do for the child, then the novelty crisis is over. Families who have been through this crisis can offer substantial help. Just to know others have faced the crisis and survived is a basic need.

Children with unusual needs are a novelty to many people. Probably more than 90% of the people in the community have little knowledge of these problems, their cause, their treatment, or the direction or course.

At this stage volunteers have found it helpful to bring parents together with professionals and other parents in the community who have solved some of these problems. When adequate resources are not available locally, then helpers can initiate efforts to develop resources to meet the particular needs of a child. Your role as a helper may be to bring together families with similar needs so that they can work together to get community action. When you recognize families with similar needs who are frustrated in their efforts to get action, you can invite them to meet with you to discuss alternate ways to develop services or secure services for their children.

THE RELIGIOUS OR EMOTIONAL CRISIS

Some parents blame themselves for the child's handicap. "What did I do to cause this terrible thing to happen to my child?" "What did my spouse do?" "Am I being punished for some sin?" Along with such questions come feelings of guilt, inadequacy, anger, despair, and desperation. Parents may desperately reject help from others or shop everywhere for some miracle solution. Shutting themselves off from friends and relatives, they may become extremely overprotective of the child. Some parents become angry with the child and reject it. The sad result is blindness to specific needs which could be faced and met.

It is not unusual for parents to face painful questions based on religious ideas and respond with emotion. The Scriptures do say, "The sins of the fathers are visited onto the sons to the fourth generation." However, they don't say this is why there are children with handicaps. The causes of delays may be traced to genetics, birth injuries or illness, but helping the child develop emotionally, mentally, and physically is more important than the cause. You help parents by pointing out their strengths and suggesting that they may have been "picked out" rather than "picked on." "Who on this street could better love and care for a handicapped child?" Often such observations are enough to eliminate the religious crisis. If not, you may want to get someone else to help.

Parents who have solved the religious problem for themselves are a valuable source of help for new parents. If there is not a parent available who is sensitive to the religious concern and also has settled it, you may have to turn to professional leaders in the church.

Some pastors are trained to understand the emotional dynamics of guilt and problems related to the painful questions involved with a handicapped child. However, some preachers know the letter of the law, but do not know the

emotional dynamics. Volunteers have found that by asking questions, they could identify those pastors in the community who were the most competent in handling these kinds of emotional crises. This same principle of identifying competent professional people is very important for a helper in the community.

REALITY CRISES

Caring for any helpless baby takes work. A handicapped child requires more care and skill. Delayed toilet training causes extensive nursing duties. A two-year old boy gets very heavy when he cannot walk, and the mother is often tired. Costs for medical care, and nursing, may get expensive. This is reality, and it's tough; but it's seldom as bad as parents fear that it will be. With the assistance of friends and community programs, most handicapped children can be cared for at home or in the community and can bring happiness and fulfillment to the parents.

HELP DURING REALITY CRISIS

Help during the reality crisis can set a tone of victory by dealing with specific needs of both the parents and the child. We can secure help for the parents in caring for the child a few hours each day so that the parent can relax, have some recreation with other family members, and pursue other interests. We can help with respite care during illnesses, and to allow for vacation periods from the heavy responsibility of caring for a handicapped child. Parents need help in doing household chores. Volunteers can help communites set up programs to provide these services. Ask your local welfare or human services office to furnish a copy of the state plan that tells how these services can be paid for by Title XX of the Social Security Act.

STATE AGENCIES

State agencies have various responsibilites for providing services for handicapped children. These agencies include Mental Health, Department of Public Welfare, and various school programs. Public health offices in the county also provide valuable services and referrals. The resources need

to be identified in your particular area, and you may be the necessary link between the person in need and the resource. The index gives places to look for resources in your area.

LIMITED RESOURCES

Families with children with specific handicaps need help to efficiently use the resources that they have such as energy, time, and money. Individuals and agencies in the community can help parents learn things to do and not to do to increase their child's rate of development, and can help in budget planning and seeking additional funds and resources when they are asked.

RECOGNITION AND ANTICIPATION

Where are the children who have needs? They are often in large families whose parents are not educated. Many of the children have parents who have difficulty solving their own problems. This means they need twice as much help with their child because they have difficulty coping with all of their problems. They do not ask for help because they do not know what to ask for, and where to go for help. These parents are more than willing to know that you are willing to help and have some valuable resources to offer them.

EARLY INTERVENTION IS CRUCIAL

"A stitch in time saves nine." With the handicapped child, wise early intervention will keep parents from giving up and literally condemning their child to a helpless life of dependence on others and unfulfillment. Early help in defining and meeting a child's needs stimulates hope and allows the potentially frustrated parent to experience the joys of seeing the child develop his potential.

Your community either has or can set up programs to train parents and provide other services for developmentally delayed children. The Office of Developmental Disabilities will provide information and financial assistance to set up programs.

THE REAL PROBLEM

When a parent asks for help, does he know what the real problem is? Parents may perceive that money is their greatest problem or some instrumental need such as a wheelchair. They want to get a child into a special program, but in fact the child must be toilet trained before he can enter the program. County Agents have been able to secure volunteers and professionals to help with toilet training for a child that is delayed. Very effective programs are available to teach a child such self-care skills as toilet training and eating, putting on clothes, speaking, and walking. Even the most delayed child can develop a great deal of independence with proper training.

NO DEAD ENDS

If you are trying to meet a need and you reach an apparent dead end: (1) restate the need and you will probably find another approach. (2) In the meantime, identify other unmet needs that you can meet.

DECIDING HOW TO CARE

The joys of success in rearing a delayed child can become more gratifying to the family than winning a ballgame or an election. Watching a child learn to walk, or feed himself, and talk, brings immense pleasure to the hard-working, dedicated parent and those who have found ways to help. One joyful parent said, "Now that I know what to do, I really enjoy helping my child develop. I am amazed at the progress which he makes every day." There is no time for such a busy, happy, productive parent to dwell on guilt or self-pity.

SUCCESSFUL PARENTS HELP OTHERS

A very effective helping technique was used by the County Agent for Children in Bedford County, Tennessee. He said, "I learned that a child with Down's syndrome had been born to a young couple, and the mother and two-day old child were still in the hospital. The parents were perplexed. They did not know what to expect with a Down's syndrome child. The father had just

started his own business with every cent invested, and consequently he was very limited on financial resources.

"I arranged for a father and his eight-year old Down's syndrome child to visit the father and his three other children in the home. The brothers and sisters had a very good time playing with the eight-year old. They discovered that he had a good personality and was progressing well in school, even though he learned slowly. The visiting father told of his adjustment problems and also shared the many satisfactions that his family was experiencing helping the child learn and develop.

MOTHER VISITED IN HOSPITAL

"At the father's request, I made arrangements for the parent and his child to meet the mother in the hospital. The mother was greatly relieved to find out more about what she could expect of her own child. When she returned home, I made arrangements for visits from another parent and their handicapped child. Friendships developed immediately, and soon others were involved with planning for the child's development.

SPECIAL PROGRAMS

"Later, I was able to make arrangements for the mother and child to travel three times a week to a nearby program for infants and toddlers. The staff there worked with the parent and child to promote development of physical abilities, communication skills, self-help skills, and social skills. The child progressed until she could enter a child development day care center in her own community. Many people became involved with the child and exciting things happened.

ROOM FOR NOVICES

"Nearly everybody involved were doing things for the first time," the County Agent said. "No one person had a clear idea what all the questions would be and certainly did not have all the answers, but in this first

critical stage for the family, none of the crises ever became dead ends. Problems were solved as they arose, lasting friendships were developed, and the community dramatically increased its efforts to provide appropriate services for handicapped children. I took the attitude our community is just as experienced and as smart as any other community. If I can get folk together, things will happen."

PARENTAL DENIAL OF A PROBLEM

Sometimes parents will not accept a diagnosis that their child will be slow developing or have a handicap. Labels such as mental retardation may turn attention away from obvious problems such as toilet training, perceptual or motor problems, and other specific behaviors that need development. Forget labels unless they are necessary to provide services, and focus on specific needs which the child or family has. Research has identified adults in institutions today because they were not assisted in self-care skills in the home. When they reached school age, they could not enter because they were not toilet trained. Eventually the child became too much for the parents to handle.

NEVER RECEIVED TRAINING

The child had been diagnosed on the basis of his functioning and placed in an institution. He never had developed his potential because he was never given the basic training. He did not have the ability to learn on his own and was therefore condemned to an unfulfilled, sad, and lonely life. Parents often have lost a child and suffer extreme damage to their self-esteem. Even the most profoundly handicapped children can be taught to move their bodies, communicate, perform self-care activities, and interact socially. With those skills, they can often remain at home without extreme hardship on the family. This is nearly always true with infants.

CRITICAL STAGE II: TODDLER

The second critical stage occurs at the toddler age. Often a child's delayed development is not apparent during infancy. Even

when a handicap is recognized, parents may not be given enough help and advice to begin training. What is done for a child at the ages of 2, 3, and 4 will make a big difference in how well and how fast the child develops.

A HEALTHY CHILD LEARNS FASTER

Convulsions from high temperatures, poor nutrition, and injury may cause the onset of developmental delay at the toddler age. When seizures, muscular weakness, and bone problems are present, medical care is especially important. Some physicians received special training in the care of developmental disabilities. Most physicians have very limited training in the non-medical aspects of developmental problems. Your area or state Office of Developmental Disabilities can refer you to special clinics for diagnosis, training, and treatment recommendations for parents, day care centers, and local physicians.

Children need as near normal experiences as possible during this period. Too much protection can restrict a child's development and increase the likelihood of physical illness. A child who is blind, lame, or deaf can still be kept healthy. The developmentally delayed child needs good health so that he can use all of his energy for learning activities. The delayed toddler needs to be in good health, at home, and receiving some special assistance in learning.

When you recognize parents are having difficulty with a toddler child, you can help by using your skills and developing new skills to identify specific needs and find ways of meeting those needs. Some specific guidelines and resources are given in the following paragraphs.

PROFESSIONAL HELP FOR TODDLERS

Many professionals are combining their talents to develop special education programs for the toddler. These programs may be called early stimulation or early intervention or child enrichment. Their purpose is to teach parents how to train their children in basic skills. Some training is offered

in the home. Other training is available in nearby centers for enrichment and development. Educators are working closely with physical therapists, occupational therapists, and psychologists to provide programs for the development of the child, physically, socially, and mentally. What they are learning by working with handicapped children has increased their skills for teaching all children.

TOILET TRAINING

Toilet training is one of the most important things for a child and his family during the toddler years. It often takes a little more skill and guidance to train a developmentally delayed child. Some communities do not have people that are trained to do fast and effective toilet training of severely or profoundly delayed children. There are effective ways to toilet train. A book by Richard M. Foxx and Nathan H. Azrin entitled TOILET TRAINING THE RETARDED describes one effective way. When schools or day care centers do not have trained people, they often will not accept children who are not toilet trained. So toilet training becomes a top priority item. In Bedford County, the County Agent enlisted the help of graduate special education students in Nashville. They worked with the school teacher, using the Azrin and Foxx method, and soon trained two non-toilet trained children. Ways to find available resources are listed in the back of this booklet.

OVERPROTECTED TODDLERS

One County Agent reported, "This child seemed to be as helpless as a newborn until I discovered some facts about his care. A very loving grandmother did everything for the child. She had not learned head control and was allowed to lie in a crib or sit in Grandma's lap all day. Even though she was past school age, she had been so protected that she functioned way below her potential."

The County Agent used the concepts developed by Nancie Finnie and helped change the expectations of the parents. With assistance from educators

and volunteers, she learned to walk and do other complicated tasks that were far beyond the original expectations. One of our friends said, "You know, the day of miracles is not over. With love, affection, training, and attention, people can still take up their beds and walk." The parents of this little girl had "accepted" her as a handicapped child, but they had not been advised of her potential. [illegible] joy they found when they were given hope and specific tasks to help their beloved child develop.

NORMALIZATION

Nancie Finnie encouraged parents to look for the potential and seek ways to develop that potential. She says:

> "Parents will be advised to avoid an overprotective attitude. If treated as a small baby in every situation and supported at all times, the child will not develop, any more than would a normal child; rather, they should look upon their child as a member of the family unit, helping him to take his place as a member of the family unit, helping him to take his place as naturally as possible in the family, and not regard themselves as his sole protector and entertainer. Having obtained as much information about the child's home environment as possible, the worker will be in a better position to cooperate with the parents, an aspect which is as important as obtaining cooperation from them... All that can be said is that the aim and treatment will be to help him become as normal a person as possible..."

County Agents have been thrilled to see parents who were dutifully and hopelessly caring for their handicapped child, change their whole outlook when the child started developing new skills.

THE PERSON BEHIND THE HANDICAP

Many people are taken aback the first time they meet a child with a severe or profound handicap. If that happens to you, that's O.K. In a short time, you will find that every child is a person with a unique personality. One person who has worked closely with a severely retarded child said, "I do not think of him as retarded anymore. He's just a child developing slowly. I now enjoy getting to know everyone, regardless of their physical characteristics." This is a very significant fringe benefit for you when you help others.

DEVELOPING OUT OF INSTITUTIONS

County Agents became involved with a small private institution where many children with profound and severe handicaps lived. The directors adopted a new philosophy and said, "By the middle of summer, every child is going to have a suntan. If they don't have head control now, we'll work until they get head control. We'll work to straighten out arms and legs, and teach their hands to hold things. We're going to take them to the parks and to church and other places unless the doctors say we shouldn't. Sure enough, by midsummer, the children had healthy looking tans and every time we visited, the staff was telling us new things that the children could do and new places they had been.

There is abundant evidence that even children with the most profound and severe handicaps will begin to develop when they are moved about, given fresh air and sunshine, love, and given specific training. You can help children and their parents by sharing this normalization program.

THIRD CRITICAL STAGE

The school-aged child is usually 5 or 6, but in some states handicapped children may be entitled to services as early as 4. Unfortunately, many children are not identified for special services until they seek to enter the classroom. If parents are not aware of special programs to cope with their child's special needs, they may keep the child out of school. At this critical stage, parents may be forced to face certain needs of their child. Counterproductive ideas, such as, "He'll grow out of it," or "He's just that way," need to be confronted with practical ways of meeting the child's needs.

LEGISLATION FOR EDUCATION OF THE HANDICAPPED

The school-aged handicapped child has often been denied adequate educational opportunity. Until recently, the handicapped child was not allowed to attend public school. The institutions were "the place for the child." Parents continue to report that the school program in some areas

does not meet the needs of their children. Concerned parents have brought successful suits against selected school districts and won requirements for the schools to provide appropriate education for all children. These decisions were based on expert testimony that all developmentally delayed persons are capable of benefitting from a program of education and training.

Parents in Tennessee report that many school districts have not developed adequate programs for their children. School officials plead limited funds and inadequate facilities, but parents and concerned citizens are devising ways to encourage and require the local school districts to provide services for their children. County Agents have helped to identify many children of school age who are not enrolled in school at all. These children are being deprived of the rights to develop their potential. Their parents are burdened with the responsibility for care and education of their child that by law is to be shared by the state. Specific strategies have been developed that you can use to work with other concerned people to instigate adequate education for all children in your community.

INDIVIDUALIZED INSTRUCTION

A child who has no physical or mental handicap can get the most from a global approach to education; however, every child can benefit more from a specific program aimed at clearly defined needs of the child. The needs are both simple and complex. One teacher insisted that a child write his assignments from the board for almost a year before any eye test revealed that the child could barely see the forms. Another child is expected to read his history assignment when he has a reading vocabulary of only 150 words and does not recognize but 10 phonic sounds.

EDUCATION AGES 4 TO 21

Developmentally delayed children can benefit from appropriate education. It does take them longer. They learn by taking small definite steps. Tennessee has passed a mandatory education law which

requires the local school districts to provide education for the handicapped until they are 21. This law makes it possible for the child to achieve a much higher level of competency and independence. County Agents work with parents and other concerned citizens to decrease dependency and the institutionalization which often follows. You can help children of this age if you know that they are not in school by finding out what the roadblock is to keeping them in school and helping them solve problems that will get back into school or keep them in school.

ELEMENTARY CHILDREN WITH DIVERSE NEEDS

CRIES FOR HELP

Children do not always cry for help in the same way. Some do not cry at all. They stand quietly in the shadows not expecting anyone to notice or care. Children are often neglected. They need your attention and love. Some children receive inadequate nutrition and medical care. They need food and medical care. Many have no one to talk to who will take time to listen. They need someone simply to listen to them and treat them as individuals. Some children have parents who cannot cope with all their own needs. Johnny or Jill is just an unfortunate burden. When you see a child walking by your home or business, do you look for signs of need? One busy man took time to see a child pressing his face against the window, looking at fresh rolls in the bakery. In a few moments, the big man and little boy with a bag clutched in his hands sat down to eat and share. When they parted a few minutes later, both were smiling radiantly. This is an example of meeting the expressive needs of the child.

PERSON TO PERSON

"They have eyes to see, but they see not. Ears to hear, but they hear not." County Agents have pointed to specific needs in their community and have found people who care. They report, "You can find people who work diligently to help others, either alone or in a group, if they know what

the needs are and something about how to meet those needs." Many volunteers have said, "I have discovered real joy and purpose in life since I learned to recognize and respond to the needs of children."

PLACES TO LOOK FOR NEEDY CHILDREN

In spite of everything children still slip through the cracks. You can look for such a child who has a parent missing from the home. The father may be in prison, in the hospital, away on the job for long periods of time, or divorced. Mother may be in the hospital, working evenings, or chronically ill at home. A child may be seen wandering the streets, truant from school, in court, or sitting alone in the park.

CHILDREN OUT OF SCHOOL

Sometimes a group of children have slipped through the cracks. In one county, a helper drew together a group of parents because all of them had a child out of school. They had had various frustrating diagnoses and evaluation experiences and had had interaction with similar doctors in the area. The group began to meet together and identify possible solutions for their problems. They considered setting up a school themselves. An inquiry was made of the state legislators for funding programs for handicapped children. They prodded the local school system to develop school programs for their children. They considered going to court. They eventually were able to get their children into a school program adapted for the child's needs. The group sought to get the director of special education of the school system to provide the services. They provided resource information on programs in the neighborhood and in adjacent counties that might serve the children in the interim before local programs were developed. They established a meeting ground for discussing the problems and seeking solutions in ther community.

THE HAWTHORNE TECHNIQUE

The County Agent used overt approaches and the "Hawthorne" technique. He sent a printout of data to the local newspaper about

the parents of variously handicapped, school-exluded children meeting to share problems and seek solutions. The agent encouraged the social workers throughout the area to seek services for children and send copies of all their written work to the director of special education to alert her to their concern for the children. The agent fed the group information on projects from information resources, set up a library for information for parents of handicapped children, and encouraged them to interact and identify the problems themselves. In this situation, the parents themselves decided what actions were effective and ineffective. They acknowledged their need to get together, their need to have direct contact with school boards; but the formal school board meetings was not a good forum. The end result was that seven children are now being served in local school programs. However, there were other parents who came in and out of the group. One parent chose not to allow his child to attend school.

DOING WHAT YOU CAN

Frequently people want to help a child in need but turn away because they cannot do all that needs to be done. What you can do may be enough to keep the child going until more help can be secured by you or by someone else who can make a different contribution. Children's needs can be divided into two categories, expressive and instrumental.

EXPRESSIVE NEEDS

Expressive needs are the easiest to meet, and the ones most often overlooked by people who are loaded with caring for other needs. The expressive or emotional needs require someone to give reassurance, friendship, moral guidance, advice, or affection. When you care, then let the child know. Many children come from homes where the mother is head of the household. Such children need a father to be a foster uncle, a big brother, to show some interest, give some time, and provide a male model to learn from.

A child needs someone around who does not have to teach or discipline. You can help so much by just listening and sharing some experiences with a child. Many volunteers or advocates like you give some time every week to stand alongside a child as a friend or big brother.

INSTRUMENTAL NEEDS

Advocates also find specific needs for transportation, clothing, assistance with securing glasses or dental care, a wheelchair, or writing a letter. Sometimes you can offer services such as filling a bicycle tire that opens the way to a rich friendship for you and the child. You can do many things easily that are virtually impossible for a young or handicapped child.

SCHOOLS GIVE INADEQUATE REASONS TO REJECT CHILDREN

County Agents have found some resistance to providing new services for some children in the community. You may need to help the local school fund and develop programs for neglected children. None of the following reasons are adequate or legal, but they may still be heard.

1. We do not have classes for your child.
2. We do not have room in our class to include your child.
3. We do not take handicapped children until they are 8 years old.
4. We do not accept handicapped children who have not reached a mental age of 5 years.
5. We do not accept children who are not toilet trained.
6. We do not accept children who have multiple handicaps such as hearing loss and blindness, cerebral palsy, etc.
7. We do not have preschool classes or kindergartens for handicapped children (where these are provided for normal children).
8. We do not accept children who do not walk.
9. We do not have enough money to provide classes for handicapped children.
10. We will put your child on a waiting list.
11. We will stop our programs for other handicapped children if you make trouble for us.
12. We will postpone your child's admission and let you know when he can come to school.
13. We are not going to educate or provide training programs for your child.
14. Your child can no longer benefit from any education or traini n.
15. We cannot send a teacher to your home to work with your child.
16. We do not have money for the type of program you child requires.
17. We cannot provide transportation.

PARENTS' RIGHTS

Courts and statutes have recognized that the Fourteenth Amendment to the Constitution of the United States applies to state education agencies and the local school systems in many situations involving handicapped children and their families. The Fourteenth Amendment says that states must provide equal protection for all its citizens and cannot deny them services offered to other citizens without fair play or what is called "due process of law." This means that when school systems wish to reduce services, discontinue services, or change services provided to children, the parents and children are entitled to at least the following things:

1. They have a right to be notified in advance of any changes being made.
2. They have a right to ask for an impartial hearing by a hearing officer who is not a part of the school system.
3. They have a right to the assistance of a lawyer.
4. They have a right to present evidence.
5. They have a right to examine all school records and other materials used in making the decision on behalf of the child.
6. They have a right to cross examine.
7. They have a right to have the proceedings recorded, and they have a right to appeal the decision in the courts if they feel it was incorrect.

FOURTH CRITICAL STAGE: PUBERTY AND ADOLESCENCE

The onset of puberty is the fourth critical stage for the child. More than ever the child's future is in his hands. He wants to live his life his way, but to some extent he needs help. If the child has learned to accept his limitations, and asks for help, he can continue to develop. However, if parents and others have given promise of too much help, the child may be too dependent and lack confidence in himself.

SYSTEMS

County Agents have conceptualized the community in terms of the following three systems that work for children. The Key Integrating Systems of Society (KISS) include the family, the school, the church, in some cases boys' clubs, etc. These systems have the primary task of assisting the child develop skills for effective living. The In Trouble Systems (ITS) come to play when the KISS System is ineffective. The ITS Systems include the courts, the mental health system, the human services or welfare system. These are entrusted with the task of correcting inappropriate behavior or inadequate adjustment to the demands of society. The third system is called the Institutional Care Endeavors (ICE) and includes the mental hospitals, the developmental schools for the mentally retarded, and other schools or programs for the blind and the physically handicapped. The ideal is for the KISS System to do its job. When problems are solved before they develop, the cost is minimal and the stress on the individual child is far less. Unfortunately once the child enters the second system, it is very hard to keep him from going into the third system, which also includes prisons and other types of incarceration for the delinquents.

The goal of every parent and every worker with children should be to prepare the child for responsible adulthood. Every youth needs a strong arm to lean on and some responsible adult to learn from. One way to help the child is to think of him as an inexperienced adult. Every community can improve the functions of its KISS for the benefit of the child.

TROUBLED TEENAGERS

Teenagers are caught in the rough sea between childhood and adulthood. They need help. Busy parents and teachers may not recognize the need until the child is in trouble. A youth in juvenile court or one who has run away from home or dropped out of school is defined as a deviant. This is not a helpful title. He needs help. There are things that we can do to

keep him from getting into trouble or to keep him from getting into additional trouble. One way is to recognize the warning signs.

WARNING SIGNS

Abrupt or persistent changes in behavior may indicate warning signs. Failure in a course at school, refusal to go to school, significant changes in weight, dressing patterns, isolation, bizarre behavior, and sleeplessness may indicate some real unmet needs. There are many other signs. Teenagers do not often ask for help unless some uncritical person makes himself available to listen. Neighbors, teachers, relatives, as well as parents, can look for these warning signs and stand ready to give a helping hand.

THE JUVENILE OFFENDER

A youth in legal difficulty welcomes someone to help. The courts are glad to find someone to help develop alternatives to prison. If you want to help, contact the juvenile judge, the sheriff, or police officer. In many cases you can keep a youth out of prison and get him started in the right direction. If you need additional help, contact a Scout official, a church youth worker, or one of the volunteer workers with youth. Some juvenile courts have programs that utilize volunteers and will provide training and guidance as you work with youth.

ALTERNATIVES TO SUSPENSION

When a child does not fit into the school system, the school may decide to suspend the child in order to keep the system functioning. Communities have found valuable alternatives to suspensions that help kids in conflict. This may include getting him a job so that he can work a part of the day and only take a couple of necessary courses in school. In some cases it involves special tutoring or counseling. A helpful adult can work with the school to provide valuable alternatives to suspension. Research indicates that children who are suspended are most likely to drop out of school and never finish their high school education.

CONSISTENT BEHAVIOR

The youth can learn to control his behavior best when adults respond consistently. Whatever response is needed should be repeated often so that the youth can know what to expect. Sometimes parents respond playfully to reckless and irresponsible behavior, and at other times respond with harsh reprisals. Even the courts are not always consistent in applying appropriate and helpful responses to youth. Anyone who works with youth needs to decide what behavior is acceptable and respond appropriately in a consistent manner.

APPROPRIATE APPLAUSE

Children and youth tend to repeat behavior that is rewarded. When a youth does something that is good, he is likely to repeat that behavior if some important person offers a meaningful congratulations. This reinforcing behavior can begin by observing a desired behavior and rewarding the behavior. Another way is to offer a reward for completing some desired task and then give the reward.

Research indicates that some youth need attention so badly that they get in trouble so that someone will notice them. To a lesser extent, youth will continue behavior that is undesired by their parents if their peers approve. Youth will respond to someone who gives them applause. Advocates who want to help can offer this applause if they will pay the price of establishing a caring relationship.

When you have established your role as a friend, you can increase or decrease behavior by your response. Undesirable behavior can be ignored or frowned upon with firmness.

FOCUS ON IMPORTANT BEHAVIOR

If you try to change every behavior of a child all at one time, he may get confused, or it becomes too complicated for everybody. We learned of a formula that helps to manage behavior. It is called the

RAID System:

R -- Rules should be as few and simple as possible.
A -- Approve or reward appropriate behavior as soon as it occurs.
I -- Ignore unwanted or inappropriate behavior while it is going on as far as is practicable.
D -- Dangerous or destructive behavior is an exception and needs firmly to be brought under control as soon as possible.

Other helpful ideas that child helpers, teachers, and many parents can use are included in the books in the appendix.

Professionals can help you work with youth who are distressing their parents by focusing on the most important aspects of behavior. The child's ability to get along with himself and others will increase his chances for success. This is true whether the child has some kind of mental or physical problem or is a normal, healthy, growing youth.

COMMUNICATION PROBLEMS

County Agents concluded that some of the problems that we called generation gaps are really communication gaps. One of the most helpful ideas we have learned about is called "Effective Listening" (Gordon, 1970). If you run across a situation in which the child says, "Nobody understands me," or "Nobody will listen," or a significant person in that child's life says, "I just don't know what's got into her," or "I can't understand what's eating on him," develop your effective listening skills and give them a try. You will discover how helpful your ear can be to some child.

LISTENING

Effective communication primarily consists of listening. We learn a great deal simply by looking at a teenager and listening carefully, not only to the words, but to the tones of voice and facial and body expressions. We can increase our understanding by asking questions and seeking clarification. This improves communication and indicates our intention to understand and accept the youth. We will learn a great deal of valuable information from listening. Perhaps the youth will also follow our role and listen to us on important issues.

SEXUAL DEVELOPMENT

Since Freud, the importance of sexual development has received increased attention. If there are no big gaps in meeting the instrumental and expressive needs of children, the sexual development will cause very little problem. Most handicapping conditions do not prevent the natural sex development.

MENTAL RETARDATION AND PREJUDICE

Irving Phillips says, "Studies have demonstrated that there is little evidence that crime, sexual promiscuity, or aberrations occur with greater frequency in the retarded. If an adolescent of normal intelligence is sexually promiscuous, he often is referred for psychiatric treatment; but, if his I.Q. is below 75, he is often committed to a state hospital." Such an approach led to forced sterilization of many mentally retarded youth and adults which resulted in deep regrets later on.

Limited opportunities for social contact with many other restraints allow retarded children to develop emotional problems. These problems need some resolution to help fulfill the child's potential. More access to outpatient psychiatric facilities are needed. Also more vocational planning for the handicapped needs to be started.

We are concerned that each child regardless of his handicap be treated with the same respect due any human being. The child and youth often needs more supervision and training in order to exercise his responsibility fully. But irreversible acts such as sterilization are invasions of personal freedom. When a community fails to provide for the developmental needs of handicapped persons as they develop, it should compensate by providing adequate programs, not just minimal custodial care. The best approach is to begin early, but it is never too late to provide the necessary care and treatment.

DEVIANCY

The word deviancy may describe the reason why handicapped children are often rejected. Intensive studies in this area indicate that the community calls deviancy any variation from the norm. The handicapped person may be different in physical features, in speech, in intellect. If this is classified as deviancy, then the youth who is handicapped may be rejected.

However, studies have indicated that handicapped children are far more like the "average" child than most people expect. He is no more likely to break the law or to deviate sexually from the norms or to cause a disruption in society than any other child. There are a few percentagewise who do break the law, commit sex crimes, and cause trouble; but these percentages are no greater, and in many cases less, than those from the "average" in society. It is very important for people like you to get to know the individual behind the handicap. In some cases, the child has a very low self-image because people have focused on his handicap and not his person. Some children seem to delight in picking on the kid who wears glasses or braces or shows some other handicap. Some children are able to handle this harrassment, and some children react negatively to it. The handicapped child needs to be seen as an individual. His handicap may be very obvious. The point is, get to know him and strengthen his assets through personal friendship.

OUR HOUSE

Some communities have arranged a program for individuals to come to know developmentally disabled children and adults in a local setting. The Nashville community arranged such a program by going to juvenile court and selecting boys who had been committed to court who had an I.Q. of 75 or below. These boys were given the opportunity to live at home and attend school in a special program called "OUR HOUSE." These boys never attracted any unpleasant attention from the community. In fact, either they were not noticed at all or people found out about the program and offered their assistance. This alternative to incarceration proved a valuable

way of giving youth the chance to be known as individuals on their own merit. Youth and adult programs that bring together volunteers who enter into a one-to-one relationship as friends to the developmentally disabled give great promise for breaking down the walls of ignorance. Building bridges on an individual basis is the best way we have found. You can begin by getting to know a youth personally and by inviting a friend to get to know the same youth or another youth on a personal basis.

FIFTH CRITICAL STAGE

The fifth critical stage in the life of the youth occurs at the time when his school years are over. What happens to the handicapped child who finishes his school work or who drops out of school prematurely? This is a very important question for every young person. It is one which the young person can answer for himself if he has received the proper education and preparation for an independent life. However, since many handicapped children have not had the proper training from the preschool years up through elementary and junior high and high school, there are many unfinished tasks. Remember, it takes the developmentally delayed child longer to achieve the necessary skills. This is true of social skills, academic skills, and vocational skills. Many schools simply have not adapted their programs so that the educably handicapped child has received enough training to function in a productive vocation. Schools have been in the habit of actually encouraging some children to drop out of school. This is justified by the statement, "They simply cannot profit by our program." County Agents have found that youth can benefit from a program that is tailored to meet their needs.

AN EXTRA YEAR

Recently in Haywood County, the vocational instructor, after much pleading, agreed to accept a child with a learning disability into the cosmetology class. The girl worked very hard and could not finish the

program in two years. She was allowed to stay a third year, and has completed the three-year program, has taken state boards, and passed them, and now is functioning as a beautician in Tennessee. This example could be repeated in many vocational areas if a child is given adequate opportunity.

High schools need to make provision in their program of vocational education for these handicapped youngsters to spend two or three, or four years, or longer learning a trade; so that they can function independently on the outside. Here is a suggested pattern. One, establish criterion for entry into the vocational areas. The special education teachers would then prepare the children and youth from the sixth or seventh grade on to enter the vocational area and meet the entrance requirements. Two, the vocational classes then would follow sequential steps based on the competency of the student so that he could achieve the necessary development in that vocational area. The vocational schools would need additional help in some cases that could be provided by a volunteer like you to work with the student on an individual basis to compensate for skill deficiencies. A child must be able to read, follow directions, and stay on task. These simple tasks can be taught to almost any handicapped child. Skills that have been developed in training the blind and the deaf and the severely handicapped can be applied to those who are not so severely handicapped.

ADULT ACTIVITY CENTERS

There is a small percentage, perhaps 5 to 10% of the handicapped, who will never be able to function independently. These youth and adults need to be prepared for a meaningful and productive life in a sheltered workshop or a similar facility as near their home and loved ones as possible. Many youth can achieve much higher independence than is expected. They do develop more with the proper training than even the experts expected a few years ago. Many communities provide adult activity centers and sheltered workshops and group homes where these individuals can live with supervision and enjoy a definite

measure of independence. The cost of operating a program in the community is very small compared to institutionalization. The benefits on the personality of the youth and on the community are immeasurable.

INSTITUTIONS AND AGENCIES

City, County, Area, State, Federal, and Private

Adult Activity Center: evaluation, training in self-care, social and vocational skills, referral, for developmental disabilities.

Agricultural Extension Agents: youth programs, educational materials on nutrition, child rearing, budgeting, etc.

Area Council on Alcohol and Drug Abuse: counseling, education, referral, transportation, emergency funds, and medicine.

Association for Retarded Citizens: volunteers, referral.

Chamber of Commerce: information, referral.

Child Development Center: evaluation, direct services, program recommendations, referral. Usually in large city near university. Respite care and adjustment training.

Churches: various programs, funds.

City Officials -- mayor, clerk, etc.: referrals and emergency transportation for medical care.

Correctional Schools: detention, education, vocational training, referral, for juvenile offenders.

County Officials -- judge, magistrates, sheriff: referral and emergency services.

Day Care Centers -- state, local, private: various levels of care for pre-school age children, meals, custodial care, training programs, physical therapy, toilet training, behavioral management programs.

Department of Education: referral, right to education services for all handicapped children ages 3 or 4 to 21.

Department of Human Services (Welfare): financial aid, child abuse, foster homes, housekeeper service, family planning, Medicaid, referral, counseling, budget planning.

Department of Mental Health: medication, diagnosis, counseling, referral, in-patient care for emotionally disturbed.

Department of Mental Retardation: diagnostic studies for mentally retarded and other developmental disabilities, residential care, respite care, day care centers, adjustment training, referral, consultation, state and regional offices.

INSTITUTIONS AND AGENCIES (CONTINUED)

Department of Public Health: speech and hearing screening, family planning, crippled children's services, vital records, eye and dental screening, health education, medication, referral. In each county.

Developmental Centers: hospital and school for mentally retarded, diagnosis, treatment, residential care, respite care, consultation, referral, family counseling. Usually one within 100 miles.

Developmental Disabilities Office -- under the Department of Mental Retardation: referral, program development. State and regional offices sponsor early intervention programs, day care, adult activity centers, diagnostic programs, etc.

Easter Seals: transportation, referrals.

Governor's Office: information, referral, funds.

Head Start: pre-school education for children ages 3-5, including handicapped children and those from low socio-economic families, noon meals, transportation.

Hospitals: medical care, physical therapy, diagnosis, referral.

Housing Authority: economical housing, youth programs, referral, meals for the elderly, etc.

Judges: funding, referral, ideas, counsel.

Juvenile Probation Officer -- county or state: counseling, referral.

Libraries: references, books, magazines, statistics.

Military Bases: medical care for children of military personnel and disabled or deceased veterans.

Public Schools: diagnostic service, classes for all handicapped children ages 4-21, speech and hearing classes, visually impaired, referral, transportation, vocational education, placement, homebound counseling. See especially special education and guidance, school superintendent, principals, social workers.

School for the Blind: residential care and training for the blind, diagnostic studies, referral, day care, materials, etc.

School for the Deaf: residential care and training for the deaf, diagnosis, referral.

Sheltered Workshops: work for disabled, work adjustment, diagnosis.

INSTITUTIONS AND AGENCIES (CONTINUED)

Social Security Administration: disability payments and Medicaid for persons disabled before age 21, referral, medical evaluation, programs for the disabled. See Federal Government.

Speech and Hearing Center: testing, instruction, referral.

State Area Vocational Schools: vocational training for persons 18 years of age and up, placement, and counseling.

State Psychiatric Hospitals: acute and chronic institutional care, psychiatric consultation, counseling, medication, referral. Contact social workers, physicians, chaplains, psychologists, etc. Usually located within 100 mile radius.

State Senators and Representatives: funding, referral.

United Fund Agencies: services, referrals.

United States Congressmen: referrals, legislation, funds.

United States Senators: referrals, legislation, funds.

Vocational Rehabilitation: services to all non-schooled handicapped people, diagnosis, medical care, appliances, vocational training, transportation, counseling, job placement.

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